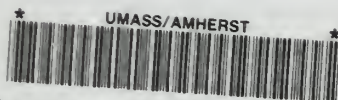


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Leominster Environment and Health Investigation

Interim Report

UNIVERSITY MICROFILMS
COLLECTION
SEP 11 1992
U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES

Prepared by:
The Bureau of Environmental Health Assessment
Massachusetts Department of Public Health
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INTERIM REPORT OF THE LEOMINSTER
ENVIRONMENT AND HEALTH INVESTIGATION

I. SUMMARY OF CURRENT ACTIVITIES

In June of 1990, the Massachusetts Department of Public Health (MDPH) received a referral from the U.S. Centers for Disease Control (CDC) regarding citizen concerns over health and environmental issues in Leominster, Massachusetts. The concerns were focused on what was reported to be an unusually high prevalence of children with autism or pervasive developmental disorder (PDD) born to current or former residents, and the possible relationship to environmental exposures related to the former Foster Grant Plastics Company. This area has come to be geographically identified as the Priest Street neighborhood. City health and governmental officials also voiced concern over the potential for current exposure to Leominster children who played at the Doyle Field playground which is adjacent to the site. Particular concern was focused on an area of the playground where the city was proposing the installation of an "Imagination Station" (i.e., a playground for toddlers).

In order to address all current environmental concerns that had been raised, and to coordinate the many tasks and activities that would be necessary to undertake in order to answer a variety of questions related to possible historical exposures and health consequences, a working group was formed. The Leominster Environment and Health Working Group (LEHWG) originally consisted of staff from the MDPH Bureau of Environmental Health Assessment (BEHA), the Leominster resident who called attention to the state superfund site and possible health effects, the Director of Public Health for the City of Leominster, and the Leominster State Representative. A few months later a researcher from the John Snow Institute joined the working group as part of their grant program to assist communities concerned over environmental health problems.

The purpose of establishing the workgroup was to identify all possible concerns that needed to be addressed, as well as to include representatives of all parties with an interest in health and environmental issues in Leominster.

The workgroup identified two major areas of concern that warranted investigation. These included:

- 1) Concern over health status:
 - Autism or related disorders
 - Cancer Incidence (in particular Hodgkins Disease which had previously been investigated in Leominster)
- 2) Concerns over the potential for human exposure to environmental contaminants:
 - Current opportunity for exposure to contaminants at the Doyle Field playground



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- Current opportunity for exposure at the Foster Grant state superfund site
- Historical exposure to environmental contaminants within a one mile radius of the Priest Street neighborhood

After review of the current literature it was established that no population-based environmental epidemiologic investigation of autism had ever been conducted and therefore, no methods had been established for systematic collection and review of appropriate medical information. Non-environmental investigations outlining case ascertainment, however, had been conducted and these methods were adapted for the ongoing investigation.

In order to address all areas of concern a variety of methods were utilized for purposes of data collection and analysis of both environmental and health outcome data. Each of these shall be addressed separately.

A. HEALTH CONCERNS

1. Evaluation of Autism Prevalence

It was determined that an evaluation of the medical records of children would help to establish whether the prevalence of autism or PDD was elevated as well as to establish the likelihood of an environmental association.

A case was defined as a child having autism or pervasive developmental disorder whose parents (one or both) lived in Leominster during the period 1960 to the present.

The MDPH utilized a number of sources of case identification: (1) Area pediatricians and otolaryngologists; (2) The Leominster Special Education Program; (3) Reports of children having autism or PDD via a private citizen reports as well as physicians attending the reported cases; (4) The Office for Children; (5) Call for cases via local news media; and (6) The Massachusetts Autism Society. A total of thirty-one names were identified by the sources previously mentioned who met the case definition. These sources reported children as having autism or a related disorder. The families were then contacted by mail in order to elicit their participation and obtain consent as well as to confirm their residential status during the period 1960-1992. Of these a total of 26 cases both responded and were eligible according to the case definition that had been established by the working group.

The working group agreed that an independent panel of experts in the fields of autism, speech communication, neurobehavioral disease, developmental disorders, and environmental epidemiology should be convened.



The panel was convened on February 11, 1992. The charge to the panel was:

- 1) Given the process the MDPH has gone through and the difficulties surrounding this issue, the panel was asked to help determine whether all potential cases of autism had been found, and if not what should be done.
- 2) The panel was asked to determine if the prevalence of autism is in fact unusual.
- 3) The panel was asked to conduct a standard review of available medical records and based upon this review determine whether the children reported to the BEHA/MDPH have autism or some related disorder with a potentially common etiology.
- 4) The panel was asked to make recommendations to the BEHA/DPH regarding further investigatory activities if it decided that the prevalence of autism in Leominster was indeed elevated.
- 5) The panel was asked to prepare a report with its findings.

The results of the panel's record review are as follows:

- o 26 cases were available for review. 21 were male and 5 were female.
- o In 6 instances, children clearly met criteria for autistic disorder.
- o In 7 cases, children clearly met criteria for pervasive developmental disorder, not otherwise specified.
- o In 6 cases, children quite clearly did not meet criteria for either condition.
- o In 7 cases, there were insufficient data available to make a decision.

The panel also noted that "if these represented the bulk of the cases in Leominster, and we were to use the generally accepted figures of 4 - 5/10,000 as the prevalence of autistic disorder and 10 -15/10,000 as the prevalence of pervasive developmental disorder, the prevalence of autism in Leominster would not seem to be excessively high. We are not yet convinced that these cases reviewed to date represent the bulk of the cases, however, and we have not calculated real prevalence rates." The full panel report is included in Appendix I.

The geographic distribution of autism and PDD cases shows that of the six children confirmed as having autism, two were born to parents who, at some time, lived within the one mile radius under investigation. The parents of the remaining cases reported that they never lived in that one

mile radius. All seven of the children having a confirmed diagnosis of PDD were born to current or former residents that ever lived in the one mile radius.

When considering usual residence (i.e., the residence in Leominster of greatest duration) two children of six with a confirmed autism diagnosis were born to parents residing within a one mile radius and five of seven confirmed PDD children were born to parents within the one mile radius. To take a conservative approach it is important to consider the greatest number of cases who had a parent residing in the one mile radius. According to the 1980 census, the population in a one mile radius of the area is approximately 8,000. This would mean that the estimated prevalence of autism is 2/8,000 and the estimated prevalence of PDD is 7/8,000.

2. Evaluation of Cancer Incidence

Cancer incidence data were obtained from the Massachusetts Cancer Registry for the most recent period available (1982-1988) to determine whether the rate of specific types of cancer in Leominster were elevated beyond that of the state as a whole.

In general, cancer incidence in Leominster is not elevated. In particular the incidence of Hodgkins Disease is at or below the expected rate. Additional cancers of concern included liver cancer and other cancers of the lymphatic system. The incidence of these particular cancers is not significantly different than the statewide average. No apparent geographic clustering of cases was noted in any particular area of the city.

B. ENVIRONMENTAL CONCERNS

1. Doyle Field

Environmental data for Doyle field were available as a result of the sampling conducted by the City of Leominster in response to concerns expressed regarding the proposed "Imagination Station."

Ten sites were sampled and each was a composite of at least four core samples of between 6-8 inches. Total lead and polynuclear aromatic hydrocarbons (PAHs) were the chemicals consistently recovered at detectable levels at almost all of the sites. These levels, however, do not represent a significant public health concern given the current guidelines for exposure to lead in soil.

Given the low levels documented in the proposed "Imagination Station" area the Bureau of Environmental Health Assessment felt that the city could proceed with plans to build the playground. As an added precaution, a recommendation was made to ensure that adequate cover be placed over the area to reduce the opportunity for exposure of children to lead and PAHs. At least 6 inches of top soil, paved or grassed, or 6 inches of stone were suggested.

2. Foster Grant State Superfund Site

Environmental data evaluated for the Foster Grant state superfund site were available due to the sampling conducted by state and federal regulatory agencies during the remedial investigation.

The data collected to date suggested localized contamination around areas of use or storage of chemicals and waste. There was no indication that contamination of off-site locations was occurring. No opportunity for exposure seems to currently exist.

Based on available information, the public health of Leominster residents is not presently being adversely impacted because no ongoing exposure to contamination on the Foster Grant/American Hoechst site has been indicated. It is expected that more information will be generated through the Department of Environmental Protection's Massachusetts Contingency Plan Phase II report. That report should include among other things, the extent of release of oil and hazardous materials, all potential migratory pathways, identification of exposure points and exposure point concentrations, background level concentrations, and characterization of risk of adverse impact to human health, safety, public welfare, and the environment. Such information in conjunction with a historical exposure assessment should provide some of the answers to remaining questions.

3. Industrial History

In order to assess the opportunity for exposure it is necessary to go beyond the 21E site and look historically at all possible sources of contamination within the one-mile radius of the state superfund site (or the Priest Street neighborhood). The MDPH is currently finalizing this assessment.

II. RECOMMENDATIONS FOR FURTHER STUDY

It is clear from the information collected and analyzed to date that no definitive judgement can be made regarding the possible relationship between the prevalence of autism among children of current and/or former residents and the historical opportunities for environmental exposure. While the data reviewed indicate that it is unlikely that current exposures to either Doyle Field or the state superfund site pose a public health risk, it is not possible to evaluate at present whether historical exposures have in some way affected the public's health.

According to the expert panel's estimates of 4-5 autism cases expected per 10,000 population and 10-15 PDD cases expected per 10,000 population, the estimated prevalence of 2/8,000 for autism and 7/8,000 for PDD would not appear excessively high. However, we agree with the panel's view that these figures may not represent the actual prevalence rates.

Based upon the activities conducted to date it is apparent that a number of steps still need to be taken which may serve to answer or address both the scientific and public concerns that have been raised. The findings of the expert panel seem to corroborate the fact that there is no systematic way to ascertain all autism cases which would allow for generation of a meaningful rate. It appears that the best way to determine whether or not the community of Leominster has an unusually high prevalence of autism or related disorders is to identify an appropriate comparison community, mimic the case finding procedures utilized for the Leominster cases and observe how the rate in Leominster differs from that community. This step is consistent with recommendations from researchers at the CDC and further discussions with members of the expert panel.

While the collection of information relative to a comparison community may serve to address some of the scientific difficulties encountered in investigating the prevalence of autism in Leominster, it can not and will not address the concerns of the public over what appears to be an escalating number of reported cases. For this reason, we will continue to attempt to obtain the names of additional cases that have been reported as a result of widespread media coverage.

To date, the MDPH has received a total of 15 new 'cases'. Only two families have responded and informed us that their children are not autistic. Efforts have continued to follow up with the remaining 13 families and to elicit additional names from individuals who know of or suspect other cases. It should be noted that while some of these activities may complement one another they are activities to be carried out separately.

Other activities that MDPH staff working on this investigation are involved with include:

- 1) Completion of the industrial history in a one mile radius of the Priest Street neighborhood to gain a better understanding of the potential opportunities for environmental exposure among residents of that area.
- 2) Contacting the seven families that the expert panel identified as having insufficient medical record information to ascertain whether additional information exists.
- 3) Coordinating with the Centers for Disease Control (CDC) in order to finalize a plan for selection of a comparison community and review of additional records.
- 4) Contacting individuals that may know of other known or suspected cases in order to establish whether or not the diagnosis of these children can be verified as well as establishing whether or not these children were born to current or former residents of Leominster.

APPENDIX I

REPORT OF MEDICAL RECORD REVIEW
LEOMINSTER AUTISM INVESTIGATION EXPERT REVIEW PANEL
MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH
BUREAU OF ENVIRONMENTAL HEALTH ASSESSMENT

Introduction

The Bureau of Environmental Health Assessment, Massachusetts Department of Public Health is in the process of investigating a suspected high prevalence of autism in the community of Leominster, Massachusetts. In the context of that investigation, names of children whose parents lived in Leominster between 1960 and present were identified.

Three sources for obtaining these names were utilized by the MDPH in conducting this investigation : private citizen reports, survey of pediatricians and otolaryngologists in the Leominster area, and the Special Education Program of the Leominster Public Schools.

This process was variable in its success. Citizen reporting identified 31 children, and 24 families responded to requests for medical information regarding these children. The public schools identified 10 children from current records, two of whom had not been identified by citizen reporting. Requests for medical records were answered in both instances. Of the 51 physicians contacted, none identified cases that had not already been identified through citizens or schools.

Thus, 26 sets of medical records were available for review. The staff of the BEHA/MDPH made strenuous efforts in recontacting families who had not responded to initial requests for records, and are to be commended for this effort.

This panel was only able to review those cases in which families had complied with requests for information. The lay press has been filled with recent reports regarding number of " cases " of autism " identified " in Leominster. These numbers have the potential to cloud the issue of this review. In a society that guards the rights of individuals to control access to their medical records, a governmental inquiry is limited by the cooperation of citizens to make sensitive data available for review.

By its nature, this report can only review those case records made available to this panel.

The Charge

In an attempt to sort out the issue of diagnosis in these 26 cases, the BEHA/MDPH sought experts in speech/language pathology, communication disorders, psychology, behavioral and developmental pediatrics, child neurology, and epidemiology outside the agency to review these records. That panel, which prepared this report, was given the following charges :

1. Given the process the MDPH has gone through and the difficulties surrounding this issue, the panel was asked to help determine whether all potential cases of autism had been found, and if not what should be done.

2. The panel was asked to determine if the prevalence of autism is in fact unusual.

3. The panel was asked to conduct a standard review of available medical records and based upon this review determine whether the children reported to the BEHA/MDPH have autism or some related disorder with a potential common etiology.

4. The panel was asked to make recommendations to the BEHA/MDPH regarding further investigatory activities if it decided that the prevalence of autism in Leominster was indeed elevated.

5. The panel was asked to prepare a report with its findings.

The panel met for the first time on 11 February 1992, at which time it was given records for review. At that time, the panel met in caucus and determined a methodology for its investigation, described below. The panel next met on 6 March 1992, and completed its review of records. This report was subsequently prepared.

Methods

The panel discussed various methods of chart review, and decided upon the following. All charts were read by all members of the panel between the first and second meetings of the panel. Each chart was assigned a primary and secondary presenter. At the time of the second meeting, the primary presenter gave a brief overview of the case history as obtained from the records. S/he then answered a series of questions the panel had agreed upon as operational ways of meeting our five charges. The secondary reviewer then offered any other pieces of information s/he felt the primary presenter had not emphasized, and the entire panel then discussed the case. The panel then made a collective answer to the questions outlined, and the chair recorded this on a data form.

It should be noted that the panel operated with remarkable

unanimity , and was able to reach all decisions by consensus.

The questions we posed ourselves are included as an appendix to this report. We specifically asked if the child had autistic disorder or pervasive developmental disorder, not otherwise specified, using the Diagnostic and Statistical Manual, Version Three - Revised, of the American Psychiatric Association; it was the unanimous opinion of the panel that this allowed for the greatest precision in decision-making. We also looked for evidence of other specific language disorders that are often confused with the autism spectrum or pervasive developmental disorders.

We noted those charts in which insufficient information was available to make a responsible determination.

Results

26 cases were available for review. 21 were male, and 5 were female.

In 6 instances, children clearly met criteria for autistic disorder.

In 7 cases, children clearly met criteria for pervasive developmental disorder, not otherwise specified.

In 6 cases, children quite clearly did not meet criteria for either condition.

In 7 cases, there were insufficient data available to make a decision.

11 children carried other specific diagnoses, most of which preclude a diagnosis of a pervasive developmental disorder. These included the six children who quite clearly did not have autism, and 4 of the 7 children with insufficient data for a decision. Thus, we would speculate that most of the " insufficient data " group would not prove to have an autistic disorder or pervasive developmental disorder were their records available.

For example, this catchment procedure included children with such diseases as infantile neuraxonal dystrophy. a degenerative and ultimately fatal disease that is not associated with autism.

20 of the children had been evaluated by more than one professional, according to the records. 14 had consistent diagnoses, 3 had conflicting diagnoses, and 3 had such incomplete records that no determination regarding the reproducibility of findings could be made.

There were no convincing cases of more than one child in a family having a pervasive developmental disorder or autism spectrum disorder, despite the inclusion of three sibling pairs in this sample.

Thus, of the 26 children whose records were reviewed, 13 have a pervasive developmental disorder, that is, either an autistic disorder or pervasive developmental disorder, not otherwise specified.

This study demonstrated several difficulties of chart review methodologies.

1. One can only review the charts made available by families and health care providers. While the media mention a large number of cases, only 26 families have signed releases for review of records.

2. A general call for cases will lead to the identification of significant numbers of inappropriate cases, given the poor public understanding of autism and related disorders. As noted, children with unrelated hereditary degenerative disorders of the nervous system were identified in the call for cases.

3. Polling the physician community was not a source of previously-unidentified material.

Thus, we cannot answer the second charge. We have no idea as to the representative nature of these 26 records, and therefore cannot use them in good conscience to speak of the prevalence of autism spectrum disorders in Leominster. If these represented the bulk of the cases in Leominster, and we were to use the generally accepted figures of 4 - 5/10,000 as the prevalence of autistic disorder and 10 - 15/10,000 as the prevalence of pervasive developmental disorder, the prevalence of autism in Leominster would not seem to be excessively high. We are not yet convinced that these cases reviewed to date represent the bulk of the cases, however, and we have not calculated real prevalence rates.

The inability of the panel to document an instance of family clustering is also noteworthy. A family with more than one case of an autism spectrum disorder would be more compelling, if circumstantial, evidence to suggest a common biologic etiology. While the failure to document such clustering does not exclude such a mechanism, coupled with the number of cases in this sample that manifestly did not have an autistic disorder, it would argue against some biologic event in Leominster.

Further information regarding the cases in the study would be helpful in the seven instances noted; clarification regarding the figures cited in recent media coverage would also be helpful. An accurate census for the number of children in the base population would be essential for proper epidemiologic evaluation.

The panel finally notes the severe limitations of this methodology (case review of " called " cases). This has produced a large number of cases clearly outside the spectrum of pervasive developmental disorders, and has produced a large number of charts that are impossible to review. If there were a decision to embark upon further investigation, direct examination of the putative cases may be a fruitful path.

The panel

Richard Clapp
Karen Levine
Valerie Chase Percia
Barry Prizant
Leonard Rapoport
David Urion, Chair

CHART REVIEW

CHILD'S NAME :
 GENDER :
 CURRENT AGE :
 AGE AT DIAGNOSIS :

REVIEWER :
 PRIMARY
 SECONDARY

DOES CHILD HAVE A FORMAL DIAGNOSIS ?	YES	NO	ID
IF SO, PLEASE STATE :			

DOES CHILD MEET CRITERIA FOR AUTISTIC DISORDER ?	YES	NO	ID
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DOES CHILD MEET CRITERIA FOR PERVASIVE DEVELOPMENTAL DISORDER, NOT OTHERWISE SPECIFIED ?	YES	NO	ID
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DOES THE CHILD HAVE A SPECIFIC LANGUAGE OR COMMUNICATION DISORDER ?	YES	NO	ID
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DOES THE CHILD HAVE A QUALITATIVE IMPAIRMENT IN VERBAL AND NONVERBAL COMMUNICATION, AS OUTLINED IN CRITERIA FOR AUTISTIC DISORDER ?	YES	NO	ID
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DOES THE CHILD MEET CRITERIA FOR ANY OF THE FOLLOWING DISORDERS :

DEVELOPMENTAL ARTICULATION DISORDER	YES	NO	ID
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DEVELOPMENTAL EXPRESSIVE LANGUAGE DISORDER	YES	NO	ID
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DEVELOPMENTAL RECEPTIVE LANGUAGE DISORDER	YES	NO	ID
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DEVELOPMENTAL COORDINATION DISORDER	YES	NO	ID
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DOES THIS CHILD HAVE ANOTHER SPECIFIC DIAGNOSIS ?	YES	NO	ID
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IF SO, PLEASE STATE :

HAS THIS CHILD BEEN EVALUATED MORE THAN ONCE	YES	NO	ID
--	-----	----	----

IF SO, ARE THE EVALUATIONS	CONSONANT
	DISSONANT
	ID

ID = INSUFFICIENT DATA

